Longer term patient management following stroke

A systematic review

Online supplement

Content

Supplementary table 1. Search terms.

Post-stroke care pathways
Structured follow-up care stroke
3 Month post-stroke review
Post-stroke disease management program
Long-term stroke management
Life after stroke

Search strategy and results

Articles were eligible if (a) they comprised post-stroke care programs, (b) the interventions were initiated within the first year after the index event, and (c) the outcome was specified, systematically assessed during follow-up, and reported. Our search strategy used the following filters: clinical trial, randomized controlled trial, meta-analysis, review, systematic review, and cohort study. The clinicaltrials.gov website was scanned for the same search terms to detect ongoing studies and studies without published results.

Duplicates and study protocols were excluded. The shortlist of remaining articles was read in full and the citations scanned for additional relevant articles. The search results are reported in the following.

Database: Medline (no limit for years or countries)

1. Post stroke care pathways/26 results
2. Structured follow-up care stroke/416 results
3. 3 month post-stroke review/89 results
4. Post-stroke disease management program/304 results
5. Long-term stroke management/1850 results
6. Life after stroke/2800 results

Database: Cochrane Library (no limit for years or countries)

1. Post stroke care pathways/30 results
2. Structured follow-up care stroke/202 results
3. 3 month post-stroke review/81 results
4. Post-stroke disease management program/35 results
5. Long-term stroke management/658 results
6. Life after stroke/3872 results

Database: clincialtrials.gov database

1. Post stroke care pathways/15 results
2. Structured follow-up care stroke/34 results
3. 3 month post-stroke review/16 results
4. Post-stroke disease management program/148 results
5. Long-term stroke management/223 results
6. Life after stroke/2878 results

Supplementary table 2. Participants, intervention details and key results and conclusions of included studies.

Study acronym or author and year of publication	Patients	Follow-up	Intervention/Review	Major results/conclusion
OSCARSS 2021[1]	All stroke, >18y	0.5	Person-centred assessment and support at home visits for carers and stroke survivors	No full implementation; no benefits of the program including QoL
SHARE 2021[2]	All stroke, >60y	1	Three home visits by nurses in 1 month after hospital discharge for guidance on the disease and care activities for the elderly people to advise and support caregivers	Burden of family caregivers increased in both groups and was higher in the control group but the difference was not significant; isolation and emotional involvement after stroke is high among caregivers
STROKE-CARD 2020[3]	Ischaemic stroke/TIA, >18y	1	Multidisciplinary program including a comprehensive multifaceted 3-month visit and access to a web-based patient portal	Reduction of cardiovascular events and improved QoL and functional outcome; no effects on risk factor control
INSPiRE-TMS 2020[4]	All minor stroke/TIA, >18y	3	Support program including feedback and motivational interviewing with 8 clinic visits over 2 years	Improved secondary prevention targets; no effect major vascular events; less events if all visits were accomplished
ICARUSS 2020[5]	All first stroke, >18y	1	Provision of link between stroke survivors, carers,	Improved risk factor targets and behavioural risk

			primary care physicians and the stroke specialists by telephone contact for support and advice; at least 3-monthly visits to the primary care physician	factors; lower systolic blood pressure, cholesterol, triglycerides and alcohol intake; no change in BMI; increased walking distance and ADLs
Struct-FU 2020[6]	All stroke, >18y	1	Interview 3 months post-stroke using a modified Post-stroke checklist; multidisciplinary stroke team interventions in case of any issues	93% of stroke survivors reported stroke-related health problems; interventions successfully initiated in a majority of patients; only few patients reported challenges not captured by the Post-stroke Checklist
iCaPPS 2020[7]	All stroke, >18y	0.5	Integrated care pathway used by family physicians who provided long-term care for stroke survivors who resided at home in the community, no specific time points	The pathway was considered cost-effective; no benefit on QoL; slight improvement of risk factor levels
AVERT 2020[8]	All stroke, <65y	1	Comparison of very early rehabilitation post-acute rehabilitation pathways in the first 3 months post stroke	Different rehabilitation pathways across the United Kingdom, Australia and Southeast Asia; overall high rates of depression, poor QoL and low rates of return to work
TACAS 2020[9]	All stroke, >18y	1	Two home visits 6 weeks apart; educational material covering common issues following stroke and risk factor management	Improved QoL and independence; more benefit if more sessions were accomplished
BISC 2020[10]	All stroke, > 18y	0.5	Carer-targeted intervention including 6 two-hour	Program acceptable to carers; group and one-to-one

			educational sessions	formats feasible; low participation rates
LAS-2 2019[11]	All stroke, >18y	5	Multiple occupational therapy sessions in a client-centred activities of daily living intervention up to 3 months	No benefit in increasing ADLs in stroke survivors in the long run; less depression in family members
Fukuoka et al 2019[12]	Ischaemic stroke/TIA, 40-80y	2.5	4 educational and supportive interviews (60 min.) in 6 months at home or at a medical facility; bi-weekly telephone calls 2 weeks by a nurse in collaboration with the primary care physician	No change in Framingham risk score at any follow-up time point; non-significant trend towards lower incidence of recurrent stroke
SUSTAIN 2018[13]	Ischaemic stroke/TIA	1	2-hour group clinics at the medical facility 2, 5, and 10 months after enrolment; regular clinic visits with the care manager at months 1 and 7 months	No effect on systolic blood pressure; lower cholesterol levels in intervention group in an ethnically diverse population
Lo et al 2018[14]	All stroke, >18y	0.16	Self-management support program with a home visit (week 1), two 2-hour community group sessions (week 2–3), and 3 follow-up phone calls (week 4)	Short term improvement of self-efficacy, outcome expectation and more satisfaction with performance of self-management behaviours
GOTVED 2019[15]	All stroke, >18y	1	Vey early supported discharge including continued rehabilitation in patient homes with a multidisciplinary team from the stroke care unit for a maximum of 1 month	No benefit on post-stroke anxiety; lower disability at 3 months, yet no effect at 12 months

EXTRAS 2019[16]	All stroke	2	Extended stroke rehabilitation service including 5 structured reviews at 1, 3, 6, 12, and 18 months post-discharge	No benefit regarding ADLs; lower rate of anxiety and depression and more satisfaction in different aspects of care in the intervention group
Rudberg et al 2018[17]	Ischaemic stroke	3	N/A	Better functional outcome at 6 months and better QoL, increased long-term survival and lower costs
LAST 2018[18]	All stroke, >18y	1.5	Monthly individualized coaching and review of progress by a physiotherapist for 18 consecutive months; first 6 meetings face-to-face in the participants' home; in the next 6 months, every second meeting could take place as a phone meeting, and during the final 6 months, 4 of the 6 meetings could take place as a phone meeting	Program showed better motor function; no benefit on functional outcome and ADLs; survivors receiving the program were more active
NAILED follow-up 2018[19]	All stroke/TIA	3	Measurements of blood pressure and blood lipids at the patients' closest healthcare facility at 1, 12, 24, and 36 months post-discharge. Interview about medication compliance and lifestyle risk behaviours	Improvement of blood pressure and cholesterol levels; higher rate of target level attainment in the long run
STANDFIRM 2017[20]	All stroke/TIA, >18y	1	Management plan by intervention nurse with independent stroke specialists. Provision of the plan to the general practitioner; home visit to provide	No benefit on cardiovascular disease risk; effect may be limited in healthcare systems providing regular follow-up and communication with general practitioners

			education and organisation of 3-monthly appointments at the general practitioner including a 6-motnh telephone call	
STANDFIRM extension 2017[21]	All stroke/TIA, >18y	2	Management plan by intervention nurse with independent stroke specialists. Provision of the plan to the general practitioner; home visit to provide education and organisation of 3-monthly appointments at the general practitioner including a 6-month telephone call	Better target level achievement for lipids at 12 months, yet no effects on any risk factor at 24 months; limited effect may be attributable to low participation of behavioural interventions
SOS 2016[22]	All stroke/TIA	1	Educational session within 1 week of discharge at home; quarterly telephone contacts at 3, 6, and 9 months, final home visit at 12 months; cholesterol and glycated haemoglobin measurements by the primary care physician at 6 and 12 months, blood pressure and body weight measurements quarterly by patients themselves or case manager; personal or telephone contacts whenever felt necessary by the patient	Pilot data showed improved risk factor target levels of blood pressure, cholesterol and BMI; better functional outcome and QoL; no cases of recurrent stroke or vascular death; further investigation in larger cohort envisaged
Damush et al	Ischaemic stroke/TIA,	0.5	Up to 6 bi-weekly telephone sessions to deliver the	No effects on self-efficacy or QoL; improvement of

2016[23]	>18y		self-management program	medication adherence
CARE4STROKE 2016[24]	All stroke	1	8-week caregiver-mediated exercises program with e-health support; exercises at least 5 times a week for 30 minutes and weekly evaluation session with the physiotherapist	No benefit on mobility; carers reported less fatigue and higher self-efficacy; improvement of ADLs, shorter length of hospital stay and fewer readmissions
NAILED 2015[25]	All stroke/TIA	1	Individualised telephone-based lifestyle counselling and assessment of pharmacological treatment; baseline blood pressure and lipid measurement and possible adjustment; new measurement 1 month after adjustment and repetition if necessary	Lower blood pressure and cholesterol levels over 12 months achieved
MIST 2015[26]	All stroke, >16y	1	Motivational interviewing face-to-face at 28 days and by phone at 3, 6 and 9 months post stroke	Improvement in self-reported medication adherence; no effects on blood pressure, cholesterol levels, QoL, anxiety and depression; no reduction in recurrent vascular events
Willeit et al 2015[27]	Ischaemic stroke	0.25	Information campaigns for the public and standardisation of a treatment pathway from stroke onset to outpatient rehabilitation	Pathway increased thrombolysis administration and improved functional outcome; no effect on mortality
Forster et al 2015[28]	All stroke	1	Assessment of stroke-related problems; number of contacts not specified but determined	No benefit on overall health, costs or QoL compared to usual stroke care coordinator service

			by the care coordinators' usual practice and patient need	
Restore4Stroke 2015[29]	All stroke, >18y	0.75	10-week self-management intervention including 6 weekly group sessions and one session at week 10 by 2 rehabilitation professionals at hospitals and rehabilitation centre outpatient facilities	Increased proactive coping and trend to better self-efficacy of partners; trend towards better QoL, lower mood complaints and participation restriction of patients
McKenna et al 2015[30]	All stroke	0.25	Self-management program including 6 weekly one-hour sessions in addition to usual rehabilitation	Trends to improvement in self-efficacy, functional activity, social integration and QoL at 6 weeks and less decline in mood and QoL at 3 months; low participation rate
Saal et al 2015[31]	All stroke	1	Post-discharge stroke support service including multiple telephone contact and home visits, informational events, training sessions, online portal, and written patient information	No benefit on physical function, QoL, depression, somatisation, or recurrent stroke; trend towards a lower risk of mortality
SMART 2014[32]	Ischaemic stroke/TIA, >18y	1	In-hospital educational sessions on pharmaceutical treatment and lifestyle modification including written and web-based educational material	Higher adherence to statin therapy but not to antiplatelet, antihypertensive or antidiabetic drugs; no reduction in recurrent vascular events
Ihle-Hansen et al 2014[33]	Ischaemic stroke or TIA	1	Outpatient visits 3 and 6 months post stroke including educational lifestyle recommendations and	Benefit on blood pressure and lipid target levels; no benefit on BMI, exercise, recurrent vascular events or

			optimization of pharmaceutical treatment; provision of a treatment plan to the general practitioner	new onset dementia
PRAISE 2014[34]	Stroke/TIA, >40y	0.5	6 weekly group workshops (90 min.) including education and self-management support	Improvement in blood pressure levels, no effect on cholesterol levels or antithrombotic use in minority urban communities
PREVENTION 2014[35]	Minor ischaemic stroke/TIA	0.5	6 monthly visits with either a nurse or pharmacist including measurement of risk factors, counselling and provision of results to the general practitioner	Higher rates of blood pressure and cholesterol target level achievement in both groups; compared to nurse-led management, active case management by pharmacists showed greater improvements
Fens et al 2014[36]	All stroke, >50y	1.5	Home visits at 1–2 weeks and 3, 6, 12 and 18 months after discharge; structured assessment on QoL and complications; provision of suitable follow-up including advice or referral to other healthcare professionals; provision of a report to the general practitioner	Positive effects on social activities at 18 months; lower depression rates in caregivers after 6 months; no benefit on QoL, ADLs, depression (patients) and anxiety
Kono et al 2013[37]	Minor ischaemic stroke	3	Advice and counselling about lifestyle at baseline, 3 months and 6 months (30 min.); lifestyle modification program comprising exercise training and salt restriction once or twice per week for 24 weeks; home exercise program with 2 sessions	Increase in daily physical activity and decrease in salt intake, improvement of blood pressure levels, trend towards lower cholesterol and blood sugar levels after 6 months; reduction of vascular events after 2.9 years; early termination of the trial because of prespecified

				early stopping rule for efficacy
YOU CALL-WE CALL 2013[38]	All mild stroke; >18y	1	Multimodal support intervention; telephone calls weekly for the first 2 months, bi-weekly during the third month, and monthly for the last 3 months provision of additional written information on stroke management as needed; referral to local community services if necessary (WE CALL); Patients receive contact number in case of questions and health problems (YOU CALL)	Benefit on participation; no effects on QoL, planned use of health services or depression; WE CALL intervention perceived as helpful by survivors, YOU CALL intervention was not used
Kim et al 2013[39]	Ischaemic stroke	0.25	Web-based program for 9 weeks; technical support by telephone	Improvement of physical exercise, diet, sense of control and health motivation for stroke patients and improvement of caregiver mastery for the primary caregiver; no effect on lipid levels; low uptake of the web-based program (63 %)
TRACS 2013[40]	All stroke	0.5	Structured in-hospital training program for caregivers	No benefit on ADLs or caregiver burden; patient and caregiver costs similar; initiation immediately after the stroke event
Cadilhac et al 2011[41]	All stroke, >18y	0.5	Self-management program with including 8 weekly sessions (150 min.)	Improved mood and better participation rates; no effects on QoL

Stop Stroke 2010[42]	All stroke	1	Tailored management advice to general practitioners, patients and caregivers at 10 weeks, 5 months, and 8 months post stroke	No effects on adherence to antihypertensive and antiplatelet drugs; no effect on smoking cessation
Hornnes et al 2010[43]	All stroke/TIA	1	Home visits (60 min.) at 1, 4, 7, and 10 months including blood pressure measurements and encouragement to visit the general practitioner if targets not met; counselling on medication compliance and healthy lifestyle	No benefit on blood pressure levels; more patients on antihypertensive drugs and better adherence to medical advice in the intervention arm
ICARUSS pilot, 2009[44]	TIA, all stroke, >20y	1	Provision of link between stroke survivors, carers, primary care physicians and the stroke specialists by telephone contact for support and advice. At least 3-monthly visits to the primary care physician	Lower systolic blood pressureand positive modification of BMI and physical activity; better functional outcome
Forster et al 2009[45]	All disabling stroke	1	Structured re-assessment for patients and their carers at 6 months post stroke using either a home assessment with case review by the hospital-located multi-disciplinary stroke team or an assessment delivered in a secondary care-based, medically led stroke review clinic with established links to therapy and social care services	No benefit on independence, emotional distress of carers, QoL, costs or health care use 6 months after completion

Allen et al 2009[46]	Ischaemic stroke	0.5	Home assessment within 1 week of discharge; review of results by a multidisciplinary stroke team; development of a care plan and provision to the general practitioner; ongoing monitoring for 6 months including home visits by a physical therapist; periodic phone calls to assess patient changes that warrant further intervention; additional home visits as needed; minimum was a weekly phone call in the first month post-discharge, then monthly for another 5 months	Improvement of stroke knowledge and lifestyle; no benefit on motor function, QoL, hospital readmissions or death
Riks-Stroke 2008[47]	All stroke	3	N/A	Poor functional outcome after stroke is an independent predictor of poor survival; interventions in the acute phase improving functional status at 3 months have favourable effects on survival in the long run
Slot et al 2008[48]	All stroke	5	N/A	Functional outcome at 6 months is associated with long-term survival; early interventions that improve functional outcome at six months may show positive effects on long-term survival
Bravata et al 2007[49]	Ischaemic stroke, >65y	5	N/A	More than 1 out of 2 patients died or were readmitted in the first year after discharge; most readmissions

				because of respiratory illness throughout the first 5 years after stroke; few stroke patients survive 5 years without a hospital readmission after stroke
Sit et al 2007[50]	All minor stroke, >18y	0.25	Education and self-management support within 8 weekly group sessions (120 min.)	Positive effects on knowledge of stroke warning signs, treatment seeking response in case of a stroke, medication adherence, blood pressure monitoring and diet; no effect on physical activity
Pedersen et al* 2020[51]	All stroke, >65y		Effect of self-management support for elderly people after stroke	Self-management interventions in older stoke survivors may be beneficial for self-management, self-efficacy, QoL, ADLs and other psychosocial outcomes; heterogeneity of interventions and different follow-up times limit conclusions
Zawawi et al* 2020[52]	All stroke, >18y		Unmet needs of stroke survivors and caregivers of stroke patients	Stroke survivors and stroke caregivers have different unmet needs which are often beyond medical and rehabilitation issues; tools to capture unmet needs are necessary; identification of unmet needs may improve post-stroke care and different outcomes
Chen et al*	All stroke		Long-term unmet needs of stroke survivors and	High prevalence of different long-term unmet needs in

2019[53]		examination of psychometric properties of the tools for assessing unmet needs of stroke survivors	stroke survivors; regular cost-effective assessments and interventions regarding unmet needs are warranted
Denham et al* 2020[54]	All stroke	Long-term unmet needs of informal carers of stroke survivors at home	High prevalence of long-term unmet needs in stroke patient carers, i.e. education, training and coping; assessments and support for carers of stroke patients are warranted
Vellipuram et al* 2019[55]	Ischaemic stroke/TIA	Lifestyle interventions including pharmacological and non-pharmacological methods targeting modifiable risk factors and their impact on the future cardiovascular events	Scarce data about effects of lifestyle interventions on cardiovascular events; data suggest increased physical activity and if delivered as part of a comprehensive program data showed minor effects on blood pressure; high-quality trials with longer follow-up and precise outcomes are required
Bridgwood et al* 2018[56]	All stroke/TIA	Effects of interventions for implementing secondary stroke prevention strategies on modifiable risk factor control, including patient adherence and the occurrence of secondary cardiovascular events with a minimum follow-up of three months	Comprehensive interventions may be associated with an improvement in blood pressure target levels; no evidence on improvement of other modifiable risk factors or reduction of vascular events; educational interventions did not improve modifiable risk factor control or prevented vascular events

Wray et al* 2018[57]	All stroke, >18y	Post-stroke self-management interventions and review of the effectiveness and investigation of the inclusion of stroke survivors with aphasia	Mixed effects of self-management programs regarding disability and QoL at 3 months or ADLs at 3 and 6 months follow-up; meta-analyses showed no benefits of self-management programs; partial reporting or inclusion of patients with aphasia
Hempler et al* 2018[58]	All stroke	Post-stroke care and current procedures on follow-up care after medical rehabilitation in Germany	No standardised follow-up care in Germany; heterogeneity in study populations; multidisciplinary cooperation in outpatient rehabilitation seems to be a key aspect of ongoing studies
Deijle et al* 2017[59]	Ischaemic stroke/TIA	Lifestyle interventions focusing on behaviourally modifiable risk factors with or without an exercise program for prevention of recurrent cardiovascular events, reducing mortality, or improving modifiable risk factors associated with cardiovascular disease	Data show effectiveness of lifestyle interventions in lowering systolic blood pressure; no effects on diastolic blood pressure, vascular events, mortality or total cholesterol
Fryer et al* 2016[60]	All stroke, 18y	Self-management programs for QoL in people with stroke	Mixed effects on QoL and self-efficacy; no superior effect for such programs on ADLs, medication adherence, participation, anxiety and depression; overall, self-management programs may be beneficial in patients living in the community

Parke et al* 2015[61]	All stroke	Self-Management support interventions for stroke survivors	High-quality evidence for supported self-management in the period after the stroke event; short term improvements in ADLs and functional outcomes and positive effects on mortality; some evidence that these interventions facilitated reintegration into the community
Lawrence et al* 2015[62]	All stroke/TIA, >18y	Multimodal behavioural secondary prevention interventions for stroke and TIA	Improvement of blood pressure levels and antithrombotic drug use; lower anxiety rates; no effects on cholesterol or blood sugar levels and no effect on dietary habits; lower rates of cardiac events and no effect on recurrent stroke/TIA or death
MacKay-Lyons et al* 2013[63]	All stroke/TIA, >18y	Effectiveness of multimodal programs of non-pharmacological interventions for prevention of secondary vascular events and risk factor control after stroke or TIA	Improvement in cardiac risk score but limited evidence (only one trial)
Fens et al* 2013[64]	All stroke, >18y	Multidisciplinary interventions for stroke patients living at home after hospitalization or inpatient rehabilitation after stroke	Limited evidence on multidisciplinary interventions in community-dwelling stroke survivors; no favourable effects on ADLs; minor positive effects on QoL - these studies combined assessments with follow-up care and

			rehabilitation interventions
Redfern et al* 2006[65]	All stroke	Complex interventions (educational or psychosocial) aimed at changing knowledge, beliefs or behaviours in patients with stroke	Primary and secondary prevention studies were not often evaluated in RCTs compared to recovery studies; RCTs less likely to influence primary outcomes than other study types; only few comprehensive interventions in stroke care adequately developed or evaluated; methodological quality seems crucial to show efficacy of interventions

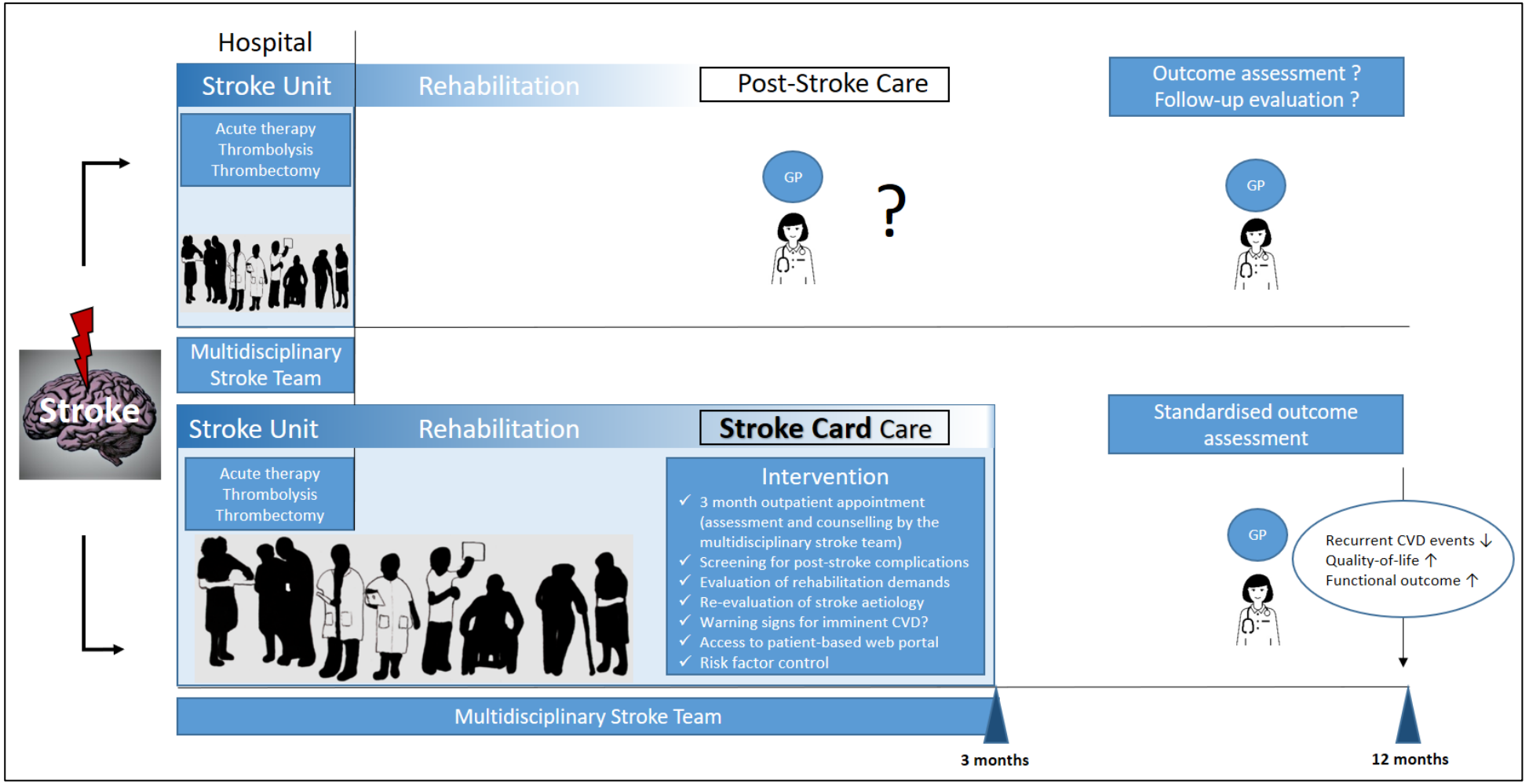
∗ Indicates a review and the focus. "All stroke" refers to both ischaemic and haemorrhagic stroke. y, years of age; QoL, quality of life; TIA, transient ischaemic attack; BMI: body-mass index; ADLs: activities of daily living; N/A, not available; RCT: randomised controlled trial. Follow-up is indicated in years.

Supplementary figure 1. Summary of ongoing/unpublished studies on post-stroke care.

Study acronym/identifier/ author/year of publication	n	Design	Intervention lead	Intervention focus			Outcomes				
				Risk factors	Compli-cations	Education or self manage-ment	Risk factor control	CVD	Quality of life	Func-tional outcome	Care-giver outcome
IMAGINE 2020[66]	272	RCT	Nurse		x	x		x	x	x	
ECO-stroke 2020[67]	432	RCT	Nurse		x				x	x	
IPCAS 2019[68]	920	RCT	HCP		x	x			x	x	
PAPASePA 2019[69]	1,210	CS	Nurse		x				x	x	x
Bektas 2019[70]	68	CT	Nurse		x	x			x		
CEOPS 2018[71]	410	RCT	Nurse	x	x	x	x		x	x	
LoTS2Care 2018[72]	200	RCT	Nurse/therapists		x	x			x		x
SUCCEED 2018[73]	516	RCT	Nurse/PA	x	x	x	x		x		
Liljehult et al 2018[74]	40	RCT	Nurse	x		x		x	x		
Milman 2017[75]	60	RCT	Nurse		x	x			x		
COMPASS 2017[76]	6,000	RCT	Physician/nurse		x			x		x	x
PREVENT 2010[77]	250	RCT	Multidisciplinary	x	x	x	x	x	x		

n, number of participants; CVD, cardiovascular events; RCT, randomised controlled trial; HCP, healthcare professional; CS, cohort study; CT, controlled trial; PA, physician assistant.

Supplementary figure 2. STROKE-CARD concept.



This figure illustrates the STROKE-CARD multidisciplinary intervention in the first three months after stroke/TIA.

GP, general practitioner; CVD, cardiovascular events.

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